# ORIGINAL ARTICLE



# Access to oncology consultation in a cancer cohort in northeastern Ontario

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### **ABSTRACT**

# **Background**

To enhance cancer symptom management for residents of Sudbury–Manitoulin District, an ambulatory palliative clinic (Pac) was established at the Northeast Cancer Centre of Health Sciences North. The Pac is accessed from a medical or radiation oncology consultation. The primary purpose of the present population-based retrospective study was to estimate the percentage of cancer patients who died without ever having a medical or radiation oncology consultation. A secondary purpose was to determine factors associated with never having received one of those specialized consultations.

### **Methods**

Administrative data was obtained through the Ontario Cancer Data Linkage Project. For each index case, we constructed a timeline, in days, of all Ontario Health Insurance Plan billing codes and associated service dates starting with the primary cancer diagnosis and ending with death.

### Results

Within the 5-year study period (2004–2008), 6683 people in the area of interest with a valid record of primary cancer diagnosis died from any cause. Most (n = 5988, 89.6%) had 1 primary cancer diagnosis. For that subgroup, excluding those with a disease duration of 0 days (n = 67), about 18.4% (n = 1088) never had a consultation with a medical or radiation oncologist throughout their disease trajectory. Patients who were older or who resided in a rural area were significantly less likely to have had a consultation.

# **Conclusions**

Specific strategies directed toward older and rural patients might help to address this important access-to-care issue.

### **KEY WORDS**

Health services accessibility, referral and consultation, rural health services, palliative care, medical records

### 1. INTRODUCTION

In Ontario, deaths from cancer were estimated to number 28,100 in 2014<sup>1</sup>. There is a recognized need to develop and implement a comprehensive palliative care strategy that will provide the best care and improved quality of life for Ontario patients and their families<sup>2</sup>; however, the availability of palliative services shows substantial variation and inequity across the province<sup>3,4</sup>. Equitable access to comprehensive palliative care could also reduce the use of aggressive end-of-life care<sup>5</sup>, which often is not the choice of palliative patients and their families<sup>6</sup>, leaves unmet needs<sup>7</sup>, is extremely costly to health care systems<sup>8</sup>, and could be avoidable<sup>9</sup>.

Sudbury–Manitoulin District is part of the North East Local Health Integration Network (LHIN), and resident cancer patients often receive care at the Northeast Cancer Centre, a Cancer Care Ontario regional cancer program located at Health Sciences North in Sudbury. Of Ontario's 14 LHINS, the North East LHIN (which serves about 4% of the Ontario population) reports the 4th highest all-cancer incidence and the highest all-cancer mortality rate. Those overall rates appear to be driven by a high lung cancer incidence and mortality in both sexes, leading to the LHIN being ranked 1 for the combined group of men and women. The incidence and mortality of colorectal cancer are high predominantly in men (ranked 2 and 1 respectively). The incidence of breast cancer in women appears to be similar to the Ontario average, and the prostate cancer incidence is underrepresented<sup>10</sup>. Those incidence trends were estimated to continue in 2014<sup>11</sup>.

Reported indicators for end-of-life care suggest that the North East LHIN performs worse than the Ontario average on some measures such as the percentage of cancer patients who visit the emergency department in the last 2 weeks of life and the percentage of cancer patients who die in an acute care hospital<sup>11</sup>. In 2011, as part of enhancing services in the district, the Northeast Cancer Centre established an ambulatory palliative clinic (Pac). Access to the clinic occurs after a patient has had a consultation with a medical or radiation oncology specialist.

To assist with palliative care planning, the present study set out to estimate the percentage of Sudbury–Manitoulin District residents who died with cancer and without a documented medical or radiation oncology consultation. It also determined factors associated with never having received one of those specialized medical consultations. The study was approved by the Research Ethics Board of Health Sciences North.

### 2. METHODS

# 2.1 Study Design and Cohort Selection

This population-based retrospective study used administrative data to define a cohort of all residents of Sudbury–Manitoulin District with cancer who died from any cause during 2004–2008.

### 2.2 Data Sources

Data were obtained through the Ontario Cancer Data Linkage Project (http://www.ices.on.ca/Research/Research-programs/Cancer/cd-link), an initiative of the Ontario Institute for Cancer Research and the Cancer Care Ontario Health Services Research Program. After completion of a data use agreement, the authors were provided with risk-reduced de-identified data.

The Ontario Cancer Registry, a comprehensive population-based cancer registry<sup>12,13</sup>, was the source for identification of index cases, which were defined as residents of Sudbury-Manitoulin District who died with any cause of death and with a valid primary cancer diagnosis record during the most recent 5-year period available at the time of data request (2004–2008). Using encrypted provincial health card numbers, the index cases were linked to three additional administrative information sources: the Ontario Health Insurance Plan (OHIP) claims database, which collects information about physician services provided to Ontario residents; the Registered Persons Database<sup>14</sup>, which contains demographic information about OHIP-eligible residents of Ontario; and Statistics Canada's Community Profiles from the 2006 census, which provides selected demographic information for residents of Canadian communities.

# 2.3 Main Outcome Measure

For each index case, we constructed a timeline in days of all OHIP billing codes and associated service dates, starting with the date of the primary cancer

diagnosis and ending with death. Our main outcome variable was consultation with a medical or radiation oncologist, which we dichotomized as "ever" or "never." "Ever consultation" was estimated based on the presence of at least one of the following OHIP billing codes at any point in the timeline: A135, A136, A435, C135, C136, C435, A445, A446, A845, C445, C446, C845, A615, C615, A345, A765, A745, A346, C345, C765, C745, C346. Because billing codes related to a medical oncology consultation can originate from more than one physician specialty, we used codes identified by Cancer Care Ontario in their reported "medical oncologist consultation indicator". Billing codes for a radiation oncology consultation were identified directly from the Schedule of Benefits for Physician Services published by the Ministry of Health and Long-Term Care under the Health Insurance Act<sup>16</sup>.

# 2.4 Variable Definitions

Number of primary cancers, dates of primary cancer diagnoses, date of death, cause of death, and year-of-death data were provided by the Ontario Cancer Registry. Duration was calculated as the number of days from primary diagnosis to death. Age (in 6 categories) and sex were obtained from the Registered Persons Database. Income quintile was derived ecologically by using Statistics Canada's PCCF+program (Postal Code Conversion File Plus, version 5E) to link median income from the Community Profiles database to the patient's postal code from the Registered Persons Database. Rural or urban residence was defined using Statistics Canada's definition of rural<sup>17</sup>.

### 2.5 Statistical Analysis

Cohort characteristics were defined using descriptive statistics and frequencies. Normality of distributions was tested, and differences by consultation status were assessed using parametric t-tests, or the non-parametric Wilcoxon rank-sum test or the chi-square test. Proportions and 95% confidence intervals (95% CIS) were constructed to estimate the proportion of the cohort without a documented consultation. Percentages were defined as 100 times the proportion. Univariable and multivariable logistic regression were used to determine odds ratios (ORS) and 95% CIS for factors associated with never having had a consultation. All statistical analyses were conducted using the Stata software application (version 12.1: StataCorp LP, College Station, TX, U.S.A.).

### 3. RESULTS

In the Sudbury–Manitoulin District, 6683 people with a valid primary cancer diagnosis record died from any cause within the 5-year period of interest.

Most (n = 5988, 89.6%) had 1 primary cancer diagnosis (Table 1).

When the analysis was restricted to the subgroup with 1 primary cancer diagnosis [excluding patients with a disease duration of 0 days (n = 67)], about 18.4% (n = 1088) had never attended a consultation with a medical or radiation oncologist throughout their disease trajectory (Table II). Common diagnoses in this subgroup were lung cancer (n = 1528, 25.8%), colorectal cancer (n = 820, 13.8%), prostate cancer (n = 581, 9.8%), and breast cancer (n = 454, 7.7%). Overall, most were 60 years of age or older (n = 5027, 85.0%) and male (n = 3294, 55.6%). Median time from primary diagnosis to death was 447 days. About 26% resided in a rural area, and an almost equal proportion of the cohort (20%) died in each of the 5 study years. When stratified by consultation status, patients who had never consulted with a medical or radiation oncologist were significantly older (p <0.01), had a shorter disease duration, and were more likely to reside in a rural area (Table III).

Multivariable logistic regression identified 3 significant and independent predictors of never attending a consultation with a medical or radiation oncologist. Older age and rural residence were associated with an increased risk of "never consultation" (adjusted or for 80 years of age and older: 7.13; 95% CI: 3.68 to 13.81; adjusted or for rural residence: 1.77; 95% CI: 1.51 to 2.06). A longer duration of disease was associated with a decreased risk of "never consultation" (or: 0.99; 95% CI: 0.99 to 0.99; Table IV).

### 4. DISCUSSION

We found that 18.4% of decedents who had 1 diagnosis of a primary cancer and who resided in Sudbury–Manitoulin District had never consulted with a medical or radiation oncologist. We are not aware of directly comparable studies, however Steyerberg *et al.*<sup>18</sup> reported that 9% of a population-based cohort of elderly esophageal cancer patients identified through the U.S. Surveillance, Epidemiology, and End Results–Medicare database were not seen by any cancer specialist. In a cohort of all Medicare-eligible patients more than 65 years of age with metastatic lung cancer, Earle *et al.*<sup>19</sup> reported that 73% had a billable event with an oncologist at some time during their illness.

TABLE I Distribution of primary cancers per person in the Sudbury–Manitoulin District decedent cohort. 2004–2008

Primary cancer (n)	Persons affected [n (%)]		
1	5988 (89.6)		
2	639 (9.6)		
3 or 4	56 (0.8)		

Conservatively assuming that 1436 deaths in patients with cancer would have occurred in our geographic area in 2014 (that is, a number identical to the number of deaths seen in 2008, the year of the most recent available data), we expect that 264 residents (95% cr. 244 to 273 individuals) might not have received the important benefit of a medical or

TABLE II Proportion of the decedent cohort (n = 5921) that ever or never had a consultation with a medical or radiation oncologist from the date of diagnosis of primary cancer to death, 2004–2008

Year	Consultation			
	Proportion	95% CI		
All years				
Ever	81.62	80.64 to 82.61		
Never	18.38	17.39 to 19.36		
2004				
Ever	81.05	78.76 to 83.33		
Never	18.95	16.67 to 21.24		
2005				
Ever	80.52	78.24 to 82.80		
Never	19.48	17.20 to 21.76		
2006				
Ever	82.43	80.25 to 84.62		
Never	17.57	15.38 to 19.75		
2007				
Ever	80.61	78.39 to 82.83		
Never	19.39	17.17 to 21.61		
2008				
Ever	83.41	81.35 to 85.48		
Never	16.59	14.52 to 18.65		

<sup>a</sup> Consultation with a medical or radiation oncologist was assumed if the patient's Ontario Health Insurance Plan record contained any of the following billing codes from the date of primary cancer diagnosis to the date of death:

Specialty	General code	Hospital inpatient code
Medical oncologist		
Internal and occupational medicine	A135 Consultation A136 Repeat consultation A435 Limited consultation	C135 C136 C435
Medical oncology	A445 Consultation A446 Repeat consultation A845 Limited consultation	C445 C446 C845
Hematology Radiation oncologist	A615 Consultation	C615
Radiation oncology	A345 Consultation A765 Consultation (under 16 years)	C345 C765
	A745 Limited consultation A346 Repeat consultation	C745 C346

TABLE III Characteristics of patients in the Sudbury–Manitoulin District who died during 2004–2008, had a valid primary cancer diagnosis record, and had one primary cancer

Variable	Patient consultation status			p Value
	Overall	Ever	Never	
Decedents	5921	4833	1088	
Age [n (%)]				
≤44 Years	127 (2.1)	117 (2.4)	10 (0.9)	< 0.01
45–49 Years	141 (2.4)	130 (2.7)	11 (1.0)	
50–59 Years	626 (10.6)	580 (12.0)	46 (4.2)	
60-69 Years	1290 (21.8)	1141 (23.6)	149 (13.7)	
70–79 Years	1958 (33.1)	1624 (33.6)	334 (30.7)	
≥80 Years	1779 (30.0)	1241 (25.7)	538 (49.4)	
Sex				
Women	2627 (44.4)	2129 (44.1)	498 (45.8)	0.30
Men	3294 (55.6)	2704 (55.9)	590 (54.2)	
Duration of disease <sup>a</sup> (days)				
Median	447	555	70	< 0.01
Range	1–5762	1–5762	1–5558	
Income quintile <sup>b</sup> [n (%)]				
1 (lowest)	1561 (26.5)	1270 (26.5)	291 (26.9)	0.38
2	1372 (23.3)	1106 (23.0)	266 (24.6)	
3	1178 (20.0)	976 (20.3)	202 (18.7)	
4	1003 (17.0)	831 (17.3)	172 (15.9)	
5	769 (13.1)	617 (12.9)	152 (14.0)	
Rural residence [n (%)]				
No	4386 (74.1)	3655 (75.6)	731 (67.2)	< 0.01
Yes	1535 (25.9)	1178 (24.4)	357 (32.8)	
Year of death [n (%)]				
2004	1129 (19.1)	915 (18.9)	214 (19.7)	0.27
2005	1160 (19.6)	934 (19.3)	226 (20.8)	
2006	1167 (19.7)	962 (19.9)	205 (18.8)	
2007	1217 (20.6)	981 (20.3)	236 (21.7)	
2008	1248 (21.1)	1041 (21.5)	207 (19.0)	

<sup>&</sup>lt;sup>a</sup> Excludes 67 decedents whose duration of disease was 0 days.

radiation oncology consultation or the opportunity to access the ambulatory Pac, if appropriate.

When the Pac was established in 2011, all referrals originated from an oncologist. More recently, referral criteria have been broadened, and about 90% of the 350 patient referrals each year currently originate from an oncologist; the remainder originate from family physicians and surgeons. The Pac has approximately 100–120 active patients at any time (advanced practice nurse, Symptom Management Program, Northeast Cancer Centre. Personal communication, 2014). Other

palliative and hospice services include a 10-bed residential hospice that opened in 2008. Since hospice inception, 89% of decedents at the facility have had a cancer diagnosis (executive director, Maison Vale Hospice. Personal communication, 2014). A "visiting hospice" outreach program and services from the Community Care Access Centre are also available.

Our finding that decedents with a rural residence in our district were less likely to have received a consultation accords with the general literature related to rural residence and decreased access to

b Excludes decedents with missing values.

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TABLE IV Univariable and multivariable logistic regression for factors associated with never having a consultation with a medical or radiation oncologist from the date of a primary cancer diagnosis to date of death

Variable	Crude result		Adjusted result <sup>a</sup>	
	OR	95% CI	OR	95% CI
Age				
≤44 Years	F	Reference	Reference	
45–49 Years	0.99	0.41 to 2.42	0.98	0.40 to 2.42
50–59 Years	0.93	0.46 to 1.89	0.85	0.41 to 1.74
60-69 Years	1.53	0.78 to 2.98	1.48	0.75 to 2.90
70–79 Years	2.41	1.25 to 4.64	2.65	1.37 to 5.14
≥80 Years	5.07	2.64 to 9.75	7.13	3.68 to 13.81
Sex				
Women	Reference		Reference	
Men	0.93	0.82 to 1.06	0.99	0.86 to 1.13
Duration of disease (per day)	0.99	0.99 to 0.99	0.99	0.99 to 0.99
Income quintile <sup>b</sup>				
1 (lowest)	F	Reference	F	Reference
2	1.05	0.87 to 1.26	0.99	0.82 to 1.22
3	0.90	0.74 to 1.10	0.87	0.71 to 1.08
4	0.90	0.73 to 1.11	0.99	0.79 to 1.23
5	1.08	0.86 to 1.34	1.13	0.89 to 1.42
Rural residence				
No	Reference		Reference	
Yes	1.52	1.31 to 1.75	1.77	1.51 to 2.06
Year of death				
2004	Reference		Reference	
2005	1.03	0.84 to 1.27	1.02	0.82 to 1.28
2006	0.91	0.74 to 1.13	0.88	0.70 to 1.10
2007	1.03	0.84 to 1.26	1.01	0.81 to 1.25
2008	0.85	0.69 to 1.05	0.85	0.68 to 1.06

a Adjusted for all variables.

appropriate health services for cancer patients in Ontario<sup>5</sup> and elsewhere<sup>20–22</sup>. Similarly, our study also demonstrates that older cancer patients might have decreased access to cancer specialists<sup>18,23</sup> and cancer services<sup>18,20,24,25</sup>. Having a consultation was also significantly associated with a longer duration of disease. However, we lacked information related to the extent of disease at diagnosis, which could have helped in better understanding whether cohort members might have had curative or palliative treatment options.

The main advantage of our study is that it is population-based, and many of the data sources are considered feasible, reliable, and valid for measuring end-of-life care in Ontario<sup>26</sup>. Earle and Ayanian<sup>27</sup>

highlighted the important benefits of using a retrospective cohort design to complement a prospective cohort approach<sup>28</sup> in studying end-of-life cancer care.

The use of administrative data does have important limitations. At the time of data request, the information required to define our cohort was available only up to December 31, 2008. The results might therefore not reflect recent trends. As well, variables that could have helped to better define the cohort and the cancer treatment received (for example, stage at diagnoses or cancer care activity level within a regional cancer centre) were not available for analysis. We used the presence of an OHIP billing code to infer an important cancer care consultation, but we lack any information about the appropriateness or quality of the care received.

b Values missing for 38 decedents.

Future research that considers associations between ever having a medical or radiation oncology consultation and other important end-of-life cancer care measures in the Sudbury–Manitoulin District (such as the use of aggressive end-of-life care, place of death, and access to palliative or hospice services) is warranted and could help in developing a better understanding of palliative care issues and informing initiatives to remove access barriers to cancer care.

# 5. CONCLUSIONS

We estimated the proportion of decedents with cancer who never received a medical or radiation oncology consultation in the Sudbury–Manitoulin District. We assume that those residents did not benefit from a specialized discussion about their cancer care, which could have included suitability for and timing of referral to a palliative care clinic. The development of strategies to address this identified gap in a potentially hard-to-reach population is important and could help to fill an identified unmet need in cancer care for patients in our area.

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# 7. CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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